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ABSTRACT

Sixty older parents were interviewed about plans for the future living arrangements of their 35 adult mentally retarded sons and daughters. Seventeen of the 35 families lived in rural communities, 18 in an urban area. Questions focused on (1) whether or not group care was perceived as an alternative to sibling care or institutional placement; and (2) whether or not formal applications had been made or plans discussed with siblings. It was found that only five families (all urban) had made any formal plans for living arrangements. Almost 40% of urban parents wanted group home placement but had not made application. No rural parents had discussed plans with a potential caretaker; 58.8% were hoping that a sibling would provide care. Larger family size in rural areas suggested less reliance on community resources. Elderly urban parents with small families tended to be undecided about future arrangements. In both rural and urban communities, younger, more educated parents were more willing to consider group home placement. Among conclusions was that, without parent application for services, providers will have difficulty predicting future need for community residential services. (JW)

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Group Homes as Resources for the Future: What do Parents Want?

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Running head: GROUP HOMES

Paper presented at the Gatlinburg Conference on Research in Mental Retardation and Developmental Disabilities, March 7, 1984. The research reported here was supported by a grant from the Tennessee Department of Mental Health and Mental Retardation.

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Group Homes as Resources for the Future: What do Parents Want?

The question of what will become of a handicapped child when the parents are no longer able to provide full-time care is of concern to all parents of such children. Worry in regard to who will care for a handicapped dependent when parents become disabled has been mentioned in articles by Birenbaum (1971), and others in the early 1960s and 1970s. Systematic attempts to study parental plans and hopes for the future have been minimal or nonexistent. Unless a parent applies for community residential services, service providers have difficulty estimating the size of their potential clientele.

Although parents may be concerned about what will happen to their child in the event of their own illness or death during any stage of the family life cycle, the need to formalize financial, legal, and living arrangements becomes increasingly important as the parents and handicapped child age. Families do have cause to be concerned about the effect of the disability or death of the primary caretaker on the lifestyle of the mentally retarded adult who lives at home. Failing to make or even discuss future living arrangements with siblings or service providers may result in the community and siblings being unprepared to take responsibility for the full-time care of a mentally retarded adult. In the worst case, the handicapped dependent becomes the responsibility of state government and is removed from family and friends through placement in a public facility.

Group homes present an alternative for the mentally retarded adult to living in a public residential facility or with a sibling. Such an alternative, however, is not equally available in all communities to persons with severe or moderate mental retardation. In rural communities, group homes may not exist as an alternative to living with a sibling. Usually in urban areas a wide range of community residential services exist, from intermediate care facilities to sheltered apartments. Parents in urban areas may also be more familiar with persons living in group homes through the adult day programs that their child may attend. Rural parents may be less familiar with the nature of group homes, and therefore less willing to consider them as alternatives to living with family members, especially if there is no group home in their community.

If a parent wants their handicapped adult to live in a group home after they can no longer provide full-time care, some advanced planning is required. Lengthy waiting lists necessitate that formal plans be made to assure the transition to a community residential program.

The present study considers whether older parents are making formal living arrangements for their adult mentally retarded sons and daughters. Questions addressed in the present study were: (a) the willingness of parents to consider a group home as an alternative to care by siblings, and the nature of those plans with a group home or siblings, and (b) has an application been

made with a group home or have the parents discussed their plans with the sibling who will become the caretaker of the future. The data presented in this paper are part of a larger research project involving many aspects of life planning for mentally retarded adults, including legal and financial arrangements and the formality of such plans. Upon completion of this project, 80 families will have been interviewed.

Method

Subjects

Interviews were conducted with 35 families of severely and moderately retarded adults living in middle Tennessee. All mentally retarded adults lived with their parents and were over age 21. Their average age was 32.3 years, with a range of 21 to 45 years. Fifteen of the 35 mentally retarded adults were severely handicapped, 5 were not involved in a full-time program. A requirement for inclusion in the present study was that at least one parent be aged 55 or older. Sixty parents were interviewed, 11 were surviving spouses, their ages ranged from 44 to 78, with an average age of 61.1 for mothers, and 61.6 for fathers. Seventeen families were living in rural communities, 18 lived in an urban area.

Parents were recruited through adult day programs, local Associations for Retarded Citizens and through other parents. Due to the nature of the subject population, a random sample

was not possible. The sample was chosen to be representative of varying income levels and educational backgrounds.

Procedure

The same interview was conducted with each family. Questions were asked regarding such basic demographic information as ages of parents and children, number of other siblings, education, and employment status. Parents were then asked if they had made any plans for the time when they would no longer be able to provide full-time care for their son or daughter. Parents were also asked where or with whom they would like their handicapped adult to live someday. All parents were asked if they had discussed their hopes or plans with a potential provider.

Results and Discussion

The families were divided into groups based on whether the adult was on a waiting list for a residential program, the type of facility, and whether the parents had discussed their plans with prospective caretakers. Families who had not discussed their hopes for living arrangements with a provider were divided into three groups. One group hoped that a sibling would care for the mentally retarded adult, another group wanted the adult to live in a group home someday, and the third group was undecided as to where their handicapped adult should live.

Insert Table 1 about here

In the total sample, parents were about equally as willing to consider a group home as a placement for the future, as they were to rely on siblings as caretakers, 37.1% and 31.7% respectively. But only 5 families had made any formal arrangements as to where their son or daughter would live. The parents who made formal plans accounted for 14% of the total sample. Parents who were uncertain as to the plans they should make regarding caretakers for their handicapped adult accounted for 17.1% of the sample. These parents were about the same age as the parents who hoped that a sibling would become providers in the future. The mentally retarded adults in the undecided group were slightly older than the adults in the other two groups, but had about the same number of siblings, 4.1, as the adults whose siblings were potential caretakers.

Insert Table 2 about here

When parents were divided into urban and rural groups, the picture changed. All of the families who had made definite plans for the future lived in an urban area. They accounted for about one-third of the urban sample. Almost 40% of the urban parents were hoping to place their child in a group home someday, but had made no formal application for services. The mentally retarded adults and parents in the group home sample were younger than the parents and adults who had been placed on waiting lists. Perhaps

the parents who hoped to place their adult in a group home did not feel pressured due to their age to make definite arrangements. The parents who hoped that a sibling would take responsibility for the mentally retarded adult were about the same age (63.8 years average) and had nearly the same size family as the parents who had applied for group home services. The undecided group of parents were the most elderly in the urban sample, their average age being 73. Their families were smaller and their mentally retarded children were also older, (37.3) than either the parents who hoped to place their handicapped adults in a group home or with a sibling.

In the rural sample, no parents had discussed their plans with a potential caretaker. The rural parents were clearly relying on family members to provide future homes for their handicapped adults, with 58.8% hoping that a sibling would become the caretaker. This group of parents were the oldest in the rural sample, with their average age being 64.2 years, and having 7.8 years of education. The mentally retarded adults in this group averaged 4.8 siblings each and were an average of 30 years old. Twenty-three percent of the rural parents indicated that they wanted their child to live in a group home some day. As a group these parents were the youngest (57 years old) and the most educated (10 years of education). Their mentally retarded adults were the oldest in the rural sample, with an average age of 34, and had the least

number of siblings, 1.7. In the rural sample, 17.6% of the parents were undecided about their plans for the future. These parents had the largest families and were similar in age and education to the group of parents whose other children were targeted as caretakers of the future. In rural communities a large family may mean that a parent has several possibilities within the family and does not need to rely on community resources for residential services.

In both the rural and urban communities, younger parents (less than 60 years old) with slightly more education and smaller families were willing to consider a group home for their son or daughter. While all but 17% of the families in both samples were able to identify a prospective caretaker, only a small group of parents actually made any formal arrangements. Very elderly parents in the city who were over 70 years old with a small family were likely to be undecided about living arrangements for their sons or daughters. This uncertainty could be a result of many factors, including: a lack of information regarding community resources, or a reluctance to separate from their handicapped child who had lived at home for many years. The mentally retarded dependents of these elderly parents are probably most at risk for having their lifestyle disrupted if a parent suddenly became disabled. Unlike the mentally retarded dependent of the undecided parent in the rural community, there are fewer possible caretakers within the family.

In the present study, three results highlight the potential social problem of finding caretakers in the community for the severely or moderately retarded adult whose parents become disabled or die: (a) very few parents had definite plans for living arrangements for their mentally retarded son or daughter, (b) even fewer parents had discussed their hopes or expectations with potential caretakers, and (c) the urban-rural split gives an indication of how the size of the family affects parental hopes regarding potential providers. In the city, the elderly parent with a small family will probably need to rely on the community or state institution as potential caretakers. In rural areas, older parents had larger families and may rely on resources within the family for help. In the rural community, it may be the under-aged 60 parent with a smaller family who will be depending on the community to care for their handicapped adult offspring within the next several years.

If the parents in the present study are representative of other older parents with mentally retarded adults, then community providers will have difficulty estimating the actual need for community residential services. One-third of all parents hoped to place their son or daughter in a group home but had not applied for services. Without an application for services, the community provider has no basis from which to predict future need. Siblings may also need advanced notice to be prepared to care for a mentally

retarded brother or sister. Without some advanced planning, the sudden disability of a parent may mean at least temporary residence in a state institution for the mentally retarded adult.

References

Birenbaum, A. (1971). The mentally retarded child in the home and the family life cycle. Journal of Health and Social Behavior, 12, 55-65.

Table 1

Preferred Residential Placements: Total Sample

	Percent	N	Age: MR Adult	Age: Parent	Education	Siblings
Waiting list for public residential facility	8.6%	3	30.3	62.8	12.5	0.6
Waiting list for group home	5.7%	2	37.0	63.7	10.2	2.0
Sibling	37.1%	13	30.2	64.0	8.9	4.3
Hoped Group Home	31.7%	11	28.1	57.0	11.3	1.9
Undecided	17.1%	6	33.0	65.8	8.4	4.1

N = 35

Table 2

Preferred Placements: Urban and Rural Parents

	Percent	N	Age: MR Adult	Age: Parent	Education	Siblings
Urban						
Waiting list for public residential facility	16.6%	3	30.3	62.8	12.5	0.6
Waiting list for group home	11.1%	2	37.0	63.7	10.2	2.0
Hoped sibling	16.6%	3	30.0	63.8	12.0	2.3
Hoped group home	38.8%	7	24.7	57.1	12.8	2.2
Undecided	16.6%	3	37.3	73.0	9.0	1.6
N = 18						
Rural						
Waiting list for public residential facility	0.0					
Waiting list for group home	0.0					
Hoped sibling	58.8%	10	30.3	64.1	7.8	4.8
Hoped group home	23.6%	4	34.0	57.0	10.0	1.7
Undecided	17.6%	3	26.3	61.0	8.0	6.7
N = 17						